

TIPS ON COLLECTING YOUR FAMILY HISTORY

Knowing Your Medical Family Tree Can Save Your Life



We inherit many things from our parents: Mother's hips, your father's eyes, ideas about family values, a love of baseball, great-grandma's wedding band. What about health patterns? Just because grandpa was overweight, developed diabetes, and died of kidney failure, does that mean that you might too? Mom had colon cancer before the age of 50. Is this your fate? Could it be your child's fate? In recent years scientists have discovered that the chance of developing certain common illnesses, like cancer, can be passed down from one generation to the next. Knowing your medical family tree allows you to take better control of your health and may even save your life. This pamphlet provides tips on how to collect family history information, answers some commonly asked questions, and suggests ways to help you overcome some potential obstacles.

Why should I collect my family history?

Collecting your family medical history is perhaps one of the most important things you can do to protect your health. Your family medical history can provide you with clues about the medical conditions that you may be more likely to develop. This will allow you to make lifestyle and health care choices that may decrease the chance of developing an illness or lessen its effect.

Why would I want to find out about health problems that run in my family if I cannot do anything about them?

You have probably heard the saying "ignorance is bliss". In this situation, it is definitely **not true**. Knowledge about your medical family tree allows you to **take action** to protect your health and that of your family. For instance, if you know that one or more of your relatives have had colon cancer, then your doctor may suggest that you change your diet and exercise habits, and undergo colon cancer screening tests earlier than the average person. Benefit: Can help to decrease the chance of getting colon cancer, or even prevent colon cancer from occurring in the first place.

When should I begin to collect this information?

Today. The sooner you have family history information, the sooner you can make healthy lifestyle choices and undergo appropriate screening tests. Contacting your elderly relatives while they are still able to provide this information is crucial to the accuracy and completeness of your family tree. If you wait, some of them may be too weak, too ill, or they may have passed away before they can give you the information you need.

My family is not close; I would feel uncomfortable asking my relatives about this.

For various reasons many people are estranged from some of their family members, or they just have had no contact with them for a long time. The following approaches may help to overcome this obstacle:

- If you want to know about the history of a branch of the family with which you are not close, you can probably contact other family members who are in touch with them. These relatives can function as “**go-betweens**”, who will help you in your quest for information. Many times when someone begins the process of gathering the family history, other relatives will become interested in the project and will decide to lend a hand. This may help to bring family members closer and resolve old conflicts.
- Sometimes it is completely impossible to contact family members, or they refuse to provide essential information. Some information about family history may be available in **public records** such as death certificates, church records, or military service records. These records can be requested by any person, and would not require contacting the actual family member or their next of kin.

I don't know where to begin!

Collecting your family history may seem like a huge task, but it's often easier than you think. The best place to begin is with your closest relatives. We suggest you follow this order:

- Begin by talking to your parents. Ask them about their parents and siblings.
- If your parents are deceased, talk to your older siblings (who may remember more details than you)
- Talk to any of your aunts and uncles who are still living. If they are deceased, their surviving spouses or children (you cousins) may be able to help you
- If your grandparents are living, talk to them as well. Ask them about their parents, siblings, nephews and nieces

Once your relatives understand that your intentions are to help **protect the health of the whole family**, they will most likely agree to help you. Additionally, you may want to offer to share the information with your relatives once all of the information has been collected and recorded in an easy to understand format.

I don't know what information I should collect!

Using a brief questionnaire (like the one we have provided) may help you organize the information. In general you will need to ask about:

- **Gender**
- **First and last name**
- **Date or year of birth** (if unknown, try to get approximate year of birth)
- **Current age**
- Any **birth defects** or congenital problems, any **chronic or major illnesses** (such as asthma, diabetes, rheumatoid arthritis, hypertension, heart disease, etc.). Include the **age at diagnosis**
- **Date/age at death** and the **cause of death**. An individual may have died of a heart attack, but have been diagnosed with cancer before. The cause of death would be a heart attack, but it would also be important to know that he/she had cancer. The names of their doctors or of hospitals where they were treated may also prove useful
- **Age at** the time of the **first diagnosis of cancer**, and where (what part of the body) the cancer started. This last point is very important because people will often say that someone died of “bone” cancer, when actually the person had breast cancer that spread to bone. It is important to know where the cancer started because that is what tells you which types of cancer you may be at higher risk for.
- History of smoking, alcohol or drug use, or any other **lifestyle factors** that may have contributed to their health problems.
- **Ethnic origin** (such as Ashkenazi/Eastern European Jewish, English, German, Italian, Mexican, etc.) of the family. This is very important because doctors know that certain diseases are more likely to affect specific ethnic groups.

Some topics, such as adoption, divorce, drug abuse, suicide, etc., may be difficult to discuss. Be sensitive to this, but explain to your family why it's important to have the most accurate history available.

I cannot remember dates or ages of my relatives, or when they were diagnosed with cancer.

It's almost impossible to remember everyone's age or birthday. **Dates and ages at the time of diagnosis and death are extremely important.** This is because we know that when common diseases like cancer occur at earlier ages they are more likely to be due to inherited risks. Medical records, death certificates and other family documents would be the best source of information. If however, you cannot find these types of documents, then here are some tips to help you or your family members remember dates/ages:

- Think in terms of **major life events**, such as weddings, births, graduations, and moving to new cities. For example, when Uncle Joe was diagnosed with stomach cancer, were you still in school? Were you already married? Had your children been born? Thinking in terms of major life events may help you pinpoint a particular date within at least 5 or 10 years.
- **Talk to other family members** and see what they remember. By working together you may arrive at a more accurate estimate of the date.

My family is scattered all over the country; it would take too much time/effort to talk to them all.

- Take advantage of family affairs like weddings, holiday gatherings, and family reunions to collect information. This provides a great opportunity to gather information on many people, clarify facts, etc. It may also allow you develop stronger ties to family members you did not know very well.
- If you don't think that your family will get together anytime soon, try to enlist the help of some key family members and split the tasks. Your siblings, first cousins, parents, aunts and uncles may be good choices. Call or write to them asking for assistance.
- It's been our experience that women are much better than men at remembering health information. If you can identify key female relatives, ask them to help.
- Are there any amateur genealogists in your family? If you learn that someone else has already gathered some of this information, make sure you talk to them.

What are some signs that an illness may be hereditary?

Almost every family will have at least one or two members with cancer, heart disease, or diabetes. Those are common illnesses, especially in older people, so most of the time they are not hereditary. However, certain features of the family tree may alert you to the possibility of an inherited risk:

- Two or more close relatives on **the same side of the family** had the same diagnosis (for example, a mother and daughter with breast cancer)
- In those who had the illness, the onset of the disease was **earlier than average** (breast or colon cancer before the age of 50)
- The illness affected people in **more than one generation** on the same side of the family
- In the case of cancer, if a person was diagnosed with **two different cancers** (for example breast and ovarian, colon and kidney, breast cancer twice) that is suspicious for inherited risk

What do I do once I have this information?

- Record it in a family tree diagram (also called "pedigree")
- Share it with your family members.
- Discuss it with your health care provider. It may lead to new health screening recommendations or lifestyle changes
- If you have questions or concerns about your family medical history and you want more detailed information about your risk and options, ask your health care provider to refer you to the **genetic counselor or geneticist in your area. Every Kaiser Permanente Medical Center has a genetics office where you can have an appointment to discuss your family history and what it means for you.** The genetic specialist can assess the impact of your medical family history on your health risks, educate you about your options, such as genetic testing, and discuss their potential benefits and limitations.

Resources for Family History/Genealogy

Libraries and Archives

The National Archives
Washington, DC (866) 272-6272
www.nara.gov

The Library of Congress
Washington, DC
www.loc.gov

Internet Resources

The National Genealogical Society
Arlington, VA (800) 473-0060
www.ngsgenealogy.org/

Family History Library and Centers
Church of Latter Day Saints
Salt Lake City, UT (800) 537-5971
www.familysearch.org

Social Security Death Index
www.familytreemaker.com/fto_ssdisearch.html

www.familytreereseach.com
Might be a good place to start
Has many good links

www.ancestry.com
Can help you create a message board to contact
relatives who may also be searching

Books/Pamphlets

Past Imperfect: How tracing your family medical history can save your life
By Carol Daus, Santa Monica Press, 1999
www.santamonica.com

The Source: A Guidebook of American Genealogy
By Sandra H. Luebking

Genealogy Online for Dummies: A Guide to Genealogy Resources on the Internet
By Matthew L. Helm and April Leigh Helm

Aids for Genealogical Research
Available free from Publication Dept. of National Archives
(866) 325-7208

Other Sources

Death certificates, cemetery records, and funeral home records usually state age, name of parents, and immediate cause of death. Death certificates are usually kept at the health department or vital statistics department of the county where the person lived or died.

The federal census for 1850 through 1920 will help to establish names, ages and place of origin for family. Information requested for the Federal Census varies, but may contain health information about certain family members.

Private institutions such as hospitals, orphanages, and special schools may give some clues about the medical history of an individual.

Diaries, family histories both written and oral, photographs. Newspaper obituaries